

Institution: Middlesex University		
Unit of Assessment: UoA4 Psychology, Psychiatry and Neuroscience		
Title of case study: Psychosocial impacts of reproductive health and wellbeing		
Period when the underpinning research was undertaken: 2000-2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
van den Akker, O.	Professor of Health Psychology	2007-present
Purewal, S.	Research Associate	01/01/2009-30/06/2014
Postavaru, G.	Research Associate	01/09/2014-31/01/2015
Daugidaite, V.	Erasmus RA	01/06/2010-31/05/2011
Payne, N.	Associate Professor	2002-present
Period when the claimed impact occurred: 2013/4-2020		
Is this case study continued from a case study submitted in 2014? Yes		
<p>1. Summary of the impact</p> <p>Our research focusses on reproductive health psychology. It has informed national and international policy and practice in many areas of mental health, employment, personal relationships and legal, ethical and human rights, and impact is demonstrated in five main areas:</p> <ol style="list-style-type: none"> 1. Surrogate motherhood: used extensively in the Law Commission's report to parliament (2019/20) calling for changes to UK law 2. Multiple births: drawn on by the Human Fertilisation and Embryology Authority (HFEA) to reduce maternal and infant morbidity and mortality 3. Pregnancy loss: informed the practice recommendations in The Nuffield Council on Bioethics' (2017) report on Non-invasive Prenatal Testing: ethical issues 4. Donor motivations: informed a number of policies and recommendations worldwide, including those from American Society for Reproductive Medicine (ASRM), The Society for Reproductive and Infant Psychology (SRIP) and the European Commission 5. Infertility treatment: contributed to UK Parliament debates on the psychological effects of funding shortages for fertility treatment and counselling, through the Fertility Network UK (FNUK) and SRIP. 		
<p>2. Underpinning research</p> <p>Undertaken over a number of decades, our research has involved integrating methodologies, ensuring originality, significance and rigour. This is demonstrated by the funding sources (Section 4), publications in high-ranking multidisciplinary international journals (Section 3), including several monographs and resource documents. Listed below is new research work, building upon those from previous REF cycles, in five specific aspects of reproductive (dys)functioning.</p> <ol style="list-style-type: none"> 1. van den Akker's research on surrogate motherhood, since it was first discussed by the British Medical Association (BMA), led to a £319,735 5-year Senior Research Fellowship NHS R&D award in 1996. Building on that, current research with colleagues (Crawshaw, Blyth, Frith, Purewal, 2007-2020) demonstrated the human rights of the surrogate-born child; the psychological effects and socioeconomic inequalities raise serious ethical questions of sufficient robustness to be of national and international concern. The UK Law Commission, tasked with providing the evidence to change existing law, the European Centre for Law and Justice, a High court judgement in South Africa, and the APA have drawn on the decades of research carried out by van den Akker and colleagues to reach their recommendations (1 section 4). 2. van den Akker, Postavaru and Purewal (funded by the British Academy) reported on substantial and costly maternal and infant morbidity and mortality following multiple births. Using meta-analytic techniques we showed unequivocally that the psychological impact of multiple births puts mothers of twins or multiples at a significantly higher risk of post-traumatic stress and its disorder compared to mothers of singletons (reference A section 3). The evidence was used in HFEA guidelines, resulting in a national reduction in multiple births and maternal/infant morbidity/mortality, and continues to be of value (2 section 4). 		

3. Daugirdaite, Purewal and van den Akker demonstrated second-trimester pregnancy loss is associated with higher levels of stress than first-trimester losses, indicating late detection and terminations for foetal abnormalities are detrimental to the psychological health of the mothers. This directly led to a call for early diagnosis and early terminations to mitigate adverse traumas in women (reference B section 3) providing evidence to the Nuffield Council on Bioethics (2017) report on ethical issues in non-invasive prenatal testing (3 section 4).

4. Purewal and van den Akker reported important individual differences between commercial and altruistic, and between white and non-white oocyte donor, motivations for and attitudes to gamete donation (reference C and D section 3). Our evidence for underlying psychological differences in gamete donations provided critical knowledge for public health recruitment campaigns and informed HFEA policy and the final European Commission report on tissue and organ donation (4 section 4).

5. Payne and van den Akker's large (N=563) survey, commissioned by FNUK, on the psychological impact of treatment for infertility showed that suicidal feelings, detrimental effects on relationships and career prospects were common, impacting upon economic input and stability. Counselling was underused due to additional funding issues. FNUK has informed Government that the evidence provided by our team (reference E, section 3) results in multiple national economic impacts of treatment and also benefitted The Work Foundation (2017) who recommended a specific workplace policy for fertility treatment (5 section 4).

3. References to the research

A) van den Akker, O.B.A. (2000) 'The importance of a genetic link in mothers commissioning a surrogate baby in the UK'. *Human Reproduction*, 15, 8, 110-117. (108 citations, Impact Factor 5.733)

B) van den Akker, O., Postavaru, G., & Purewal, S. (2016) A systematic review and meta-analysis of the psychosocial consequences of twins and multiple births following medically assisted reproduction. *RBM Online*. 33(1), 1-14. doi.org/10.1016/J.rbmo.2016.04.009. (7 citations, Impact Factor: 3.22)

C) Daugirdaite, V., van den Akker, O., & Purewal, S. (2015) Posttraumatic stress and posttraumatic stress disorder after termination of pregnancy and reproductive loss: a systematic review. *Journal of Pregnancy*, 646345. doi.org/10.1155/2015/646345 (89 citations)

D) Purewal, S., & van den Akker, O.B.A. (2009) Systematic review of oocyte donation: investigating attitudes, motivations and experiences. *Human Reproduction Update*, 15, 499-515. doi.org/10.1093/humupd/dmp018 (149 citations, Impact Factor 14.48)

E) Payne, N., Seehan, S., & van den Akker, O.B.A. (2018). Experiences and psychological distress of fertility treatment and employment. *Journal of Psychosomatic Obstetrics and Gynecology*, 40, 156-165. doi.org/10.1080/0167482X.2018.1460351 (6 citations, Impact Factor 2.33)

F) Purewal, S., Chapman, S., & van den Akker, O. (2018) Depression and state anxiety scores during assisted reproduction treatment are associated with outcome: a meta-analysis. *Reproductive BioMedicine Online*. 36(6), 646-665. (35 citations, Impact Factor 3.218)

4. Details of the impact (sources to corroborate the impact provided as attachments 1-10)

1. The Law Commissions (UK) consult widely when drawing up programmes of law reform, to ensure that their work is as relevant and informed as possible. Consultation for the Law Commission of England and Wales' 13th Programme of Law Reform was launched on 11 July 2016 and ran until 31 October 2016. In this consultation, the Law Commission of England and Wales suggested surrogacy as a possible law reform project. This suggestion prompted the highest number of responses of all the projects in the 13th Programme. That this was an area in need of reform was also supported by consultees responding to the consultation on the 10th Programme of the Scottish Law Commission.

The Law Commission ran a public consultation and round table meeting (01/2019) to gather evidence on the psychosocial, ethical, legal and medical aspects of surrogate motherhood in the UK and abroad, with a view to reform current law. This initial consultation benefited from the contribution of the multidisciplinary research and practice expertise of the Project Group on Assisted Reproduction (PROGAR: BASW) (1) of which van den Akker is a long-term member. Law Commission members also attended our SRIP funded workshops. Following these consultations and meetings, the Law Commission's report to parliament (2019/20) calling for changes to current UK law, drew extensively on van den Akker's research (reference A, section 3) and expertise on surrogacy, including a recent monograph containing the bulk of the papers referred to in the Law Commission document (2). The human rights of the child in surrogacy, the impact of non-birth registrations by recipient parents, socioeconomic inequalities and psychological effects of the absence of a genetic and/or gestational link with a baby on all parties – all factors demonstrated by this research - were acknowledged as integral considerations in the proposed changes to current law. Our expertise in this research area is further demonstrated by the Law Society's report acknowledging, by name, our contribution to the report (specifically see page 21 sections 1.111 and 1.112, and sections 2, 5 and 12 which directly cites our research). The report is accompanied by a draft Bill to change the law in line with the recommendations with the result that this will lead to a new, standalone, Surrogacy Act, which would govern improved surrogacy arrangements and their consequences in the UK.

In addition to national impacts, van den Akker's research also demonstrates surrogacy operates contrary to numerous international and European law provisions, especially regarding human dignity, adoption, protection of women and children and trafficking in human persons as cited in the European Centre for Law and Justice Report and CAFFCASS eLearning materials. The Pretoria High Court handed down judgement in the constitutional challenge to the 'genetic link requirement' for surrogate motherhood. van den Akker's research evidence impacted on the conclusion of the judgement to allow the surrogacy to proceed.

2. The HFEA launched One at a Time in 2007 (van den Akker was invited onto the advisory board) to tackle the high multiple birth rate following IVF which was 20 times higher than natural conception. Multiple pregnancies and births are riskier for the mother and her babies and the effects can be lifelong. Following the 2014 Impact Case study, the HFEA continues to draw on our research (van den Akker, Postavaru, & Purewal, reference B, section 3) into the adverse psychological consequences of twins and multiple births following treatment for assisted conception. They have tightened national restrictions on multiple embryo transfers, acknowledging the substantial and increased risks of psychological morbidity and mortality in mothers and babies, as demonstrated in the HFEA's reference to our meta analytic research, in addition to the already existing huge body of evidence linking physical morbidity and mortality to multiple births. The One at a Time Campaign met their multiple birth target of 10% for the first time in 2017, having reduced from 24% in 2008, showing substantially reduced maternal and infant morbidity and mortality.

3. The Nuffield Council on Bioethics' (2017) report on Non-invasive Prenatal Testing: ethical issues, has used our research in its practice recommendations to prevent post-traumatic stress and its disorder in reproductive losses (Daugirdaite, van den Akker, & Purewal, reference C, section 3). Its contribution, that early diagnosis of foetal abnormality could lead to early terminations of affected fetuses, mitigating substantial trauma caused by later diagnosis and later terminations (3) ensures health and wellbeing impact through improved clinical interventions. Down's syndrome, for example, is detected in more fetuses when non-invasive prenatal testing is introduced as a second stage screening test following the combined test, and this might result in some late terminations being avoided. It is therefore recommended in the report, that tests are offered without delay, particularly to women with a high risk following non-invasive prenatal testing: 'A delay in diagnosis therefore, could be viewed as increasing harm to the pregnant woman in cases when a termination is being considered. It will be important that women are able to go straight to diagnostic testing after a high chance combined test result if they wish'.

4. The Ethics Committee of the ASRM, has recommended that the use of adult intra-familial gamete donors and gestational surrogates is ethically acceptable when all parties are fully informed and counselled. Our research provided much-needed data, leading to recommendations that clinics participating in intra-familial arrangements should spend additional time counselling participants ensuring they made free, informed decisions (4).

Our research also led to a SRIP funded dissemination workshop (van den Akker and Crawshaw, 2014) to develop a research and practice-informed approach to family-building theory through donor conception. It was attended by the DoH, DfE, DoJ and practitioners (5), who all committed to incorporate the recommendations in future legislation and practice recommendations.

The final report for the 'Economic landscapes of human tissues and cells for clinical application in the EU' - by the European Commission, 2015 used three of our studies (Purewal and van den Akker, reference D, section 3) to demonstrate the range of psychological and cultural factors relevant in donation in clinical practice (6). The most recent Government's advisory committee report on Blood, tissue and cell donor selection criteria, 2017 has drawn on our research and recommended targeted recruitment is necessary in gamete donation practice particularly for BAME communities (7), ensuring improved availability success rates of an ethnically wider range of gametes meeting the needs of the diversity of infertile populations in the UK.

5. Fertility Network UK (FNUK), the leading British fertility network for patients, donors and practitioners funded our research (Payne, Seehan, & van den Akker, reference E, section 3). This was one of the largest UK surveys demonstrating the prevalence of significant psychological morbidity at various stages of treatment, compounded by the lack of funding for counselling and further concerns about employment. FNUK is developing a resource for employers to provide better support, ensuring information is available and work does not worsen during this stressful time, and the impact on and risks to work are minimised. FNUK also used the evidence in a parliamentary debate urging for improved access and practice. Purewal, Chapman and van den Akker's research (reference F, section 3) also made a material contribution to the APA Resource Document advocating counselling (8) ensuring the impact of psychological effects of treatment are incorporated in treatments.

Our work with FNUK on the psychological effects of funding shortages for fertility treatment and counselling, were integral to the UK Parliament's debate on funding strategies. This led to another SRIP funded multidisciplinary and practice workshop to disseminate the evidence to business and trade unions (van den Akker et al, 2019) (9). The Work Foundation's Health at Work Policy Unit (HWPU) provides evidence-based policy recommendations and commentary on contemporary issues around health, wellbeing and work. Following the SRIP funded workshop, the Work Foundation produced a report on Women's reproductive health and work (2017), which draws heavily on our research (Payne, Seehan, & van den Akker, reference E, section 3). The evidence led to recommendations for action which were incorporated in its policy (10):

- Improve recognition of women's reproductive health in workplace policy and processes; Provide a pathway for female staff to access confidential work support;
- Recommendations for the Joint Work and Health Unit; Improving access to evidence-based advice and support through government services and support.
- Recognition of, and clear guidance from government on women's health issues
- Raising awareness and encouraging and supporting employers (e.g. via The Advisory, Conciliation and Arbitration Service (ACAS), and the Chartered Institute of Personnel and Development (CIPD)).
- Review and improve clarity over legal status of reproductive health conditions. The Department for Work and Pensions should update assessment criteria for welfare support to recognise the debilitating nature of some reproductive health conditions, particularly infertility, under the Equality Act 2010 as a long-term, disabling chronic condition.

Furthermore, despite Infertility being recognised as a long-term condition by both the World Health Organisation and the Department of Health, in practice it is not viewed in the same way as other long-term conditions according to the House of Commons Library Debate Pack (2017)

'Decommissioning of IVF and other NHS Fertility Services'. Parliamentary debates about inequalities in treatment have now drawn attention to the lack of consideration of the mental distress associated with infertility on the national policy stage, and the impact on wider quality of life, including in terms of employment (House of Commons Library Debate Pack, 2017). Finally, more recent exposure on BBC News (22/04/2020) during the Covid 19 lockdown, advised a larger audience of employers and employees to improve current and future workplace practice strategies and policies.

Sources to corroborate the impact

Listed here and all Pdf's attached and numbered.

- (1) Project Group on Assisted Reproduction (PROGAR: BASW)
- (2) Surrogacy Law Commission Report
- (3) Nuffield Report
- (4) ASRM Report
- (5) SRIP workshop Report
- (6) European Commission Report
- (7) Govt. advisory committee Blood, cell and tissue donor selection
- (8) APA resource document
- (9) SRIP workshop report
- (10) The Work Foundation Policy and BBC News report 22/04/20 re Covid effects.